

Family Caregiver Skills in Medication Management for Hospice Patients: A Qualitative Study to Define a Construct

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Objectives. To propose a theoretical construct of family caregiver skills in effective medication management for home hospice patients.

Methods. Semistructured face-to-face interviews were conducted with 22 hospice providers (14 nurses, 4 physicians, and 4 social workers) and 23 family caregivers (10 daughters, 4 wives, 2 husbands, and 7 others) of elderly patients (≥60 years old) who were receiving home services from four hospice care programs in the Chicago metropolitan area.

Results. Although both groups identified similar skill sets, hospice providers emphasized technical skills such as administering medications, and family caregivers valued management skills such as organizing medications, coordinating with hired caregivers, and providing care to patients who resisted treatment. We defined effective medication management in hospice as caregivers' ability to effectively relieve symptoms with pharmacological interventions by successfully utilizing skills related to *teamwork* (coordinate with hospice providers and with other family or hired caregivers), *organization* (acquire, store, track, and discard medications), *symptom knowledge* (recognize and interpret common symptoms), *medication knowledge* (understand the basics of pharmacology and medication administration), and *personhood* (understand and respond to the patient's needs).

Discussion. The proposed construct of medication management skills in hospice will help guide future development of training interventions and clinical assessment tools.

Key Words: Caregiver competence—Caregiving—Pain management—Palliative care—Symptom control.

MANY relatives and friends play key roles in providing care to older adults with chronic disease, disability, and life-limiting illness (Piercy, 2007; Port et al., 2005; Williams et al., 2008). In family caregiving research, skill has largely been conceptualized in terms of coping rather than in terms of skills for effectively providing care to the ill person (Pearlin, Mullan, Semple, & Skaff, 1990). Family caregivers are directly engaged in the daily care of home hospice patients (Hauser & Kramer, 2004). Medication management is a critical, yet complex, responsibility because hospice patients often require potent pharmacological interventions to relieve distressing symptoms. Evidence suggests that family caregivers feel inadequately prepared to manage medications (Schumacher et al., 2008), and adequate symptom control for patients is often not achieved (McMillan & Moody, 2003).

Prior studies have examined aspects of health care among elders living at home, such as self-management of medications, pain management, and caregiving, including medication management by caregivers (Travis, Bernard, McAuley, Thornton, & Kole, 2003; Travis, Bethea, & Winn, 2000).

This study contributes to previous research by developing an overall construct and defining specific domains of medication management skills for family caregivers of hospice patients. Such an effort is a necessary initial step toward creating a standardized clinical assessment of caregivers' skills and developing theory-based interventions for skill improvement.

This study proposes a multidimensional construct of family caregiver skills in medication management for home hospice patients. We first present background on previous research related to family caregiving and medication management in elderly hospice patients. We then provide findings from a qualitative analysis of interviews with hospice providers and family caregivers of hospice patients. Based on professional and family caregiver's perspectives, we develop a theoretical construct and discuss its relevance for clinical practice and quality of care.

Background

In 2007, about 42% of all hospice patients received care in their private residence and 28% in a long-term care facility

(National Hospice and Palliative Care Organization, 2008). Among those living in private residences, 90% lived with someone who provided most of the daily hands-on care (Haupt, 2003). Families are increasingly involved in end-of-life care for patients in hospice (Given, Given, & Kozachik, 2001). Although more than 80% of family caregivers report managing medications for hospice patients, less than 60% receive medication management assistance from their hospice (Carlson, Morrison, Holford, & Bradley, 2007; Letizia, Creech, Norton, Shanahan, & Hedges, 2004). Yet, little is known about how family caregivers actually manage medications or what skills or training they need to effectively manage medications at home when dealing with the multiple symptoms associated with the end of life.

Most hospice patients experience multiple distressing symptoms including pain, shortness of breath, delirium, anorexia, constipation, nausea, and vomiting (Emanuel, Fairclough, Slutsman, & Emanuel, 2000). These symptoms tend to change more unexpectedly and frequently as death nears. The goal of symptom management using pharmacological interventions is to control symptoms while avoiding adverse side effects. In practice, however, pain and other symptoms for patients near the end of life remain often underrecognized and undertreated by professional and family caregivers (McMillan & Moody, 2003; McMillan & Small, 2002).

Pain is among the most distressing symptoms affecting hospice patients (Dobratz, 2001). Caregivers are expected to administer a variety of medications including opioids to manage pain (Portenoy, 2007). They may simultaneously administer extended-release and immediate-release drugs "around the clock" in a variety of formulations including pills, liquids, patches, and suppositories. Caregivers need to be vigilant about common side effects of opioids such as constipation, nausea, and vomiting and need to administer additional prescriptions of laxatives or anti-nausea agents to counteract them (Portenoy, 2007).

Other common symptoms near death can also be alleviated with appropriate medications. For example, shortness of breath may require opioids, cough suppressants, and anti-anxiety agents (Qaseem et al., 2008). For delirium, common treatments include antipsychotic agents with potential severe anticholinergic and sedative side effects. The complex nature of symptoms and drug regimens associated with end-of-life care therefore requires careful and skilled medication management. Developing a deeper understanding of caregiver skills in medication management is an important step toward managing symptoms and facilitating the goals of end-of-life care.

Being skilled in caregiving requires transitioning from knowing *what* to do to knowing *how* to perform (Brown & Stetz, 1999). General caregiving skills have been conceptualized as the ability to successfully perform nine processes: monitoring, interpreting, making decisions, taking actions, making adjustments, providing direct care, accessing resources, working with the ill person, and negotiating the

health care system (Schumacher, Stewart, Archbold, Dodd, & Dibble, 2000). These skills are considered transactional, meaning caregivers should be able to effectively respond to changes in a patient's illness (Schumacher, Beidler, Beeber, & Gambino, 2006).

Skills in medication management typically have been discussed in the literature as a particular task of direct care to which caregivers are expected to adhere (Buelow & Smith, 2004). However, in concert with a transactional view of caregiving, medication management may be better understood as a set of synthesized processes involving judgment rather than discrete tasks. For example, medication management may require a high level of cognitive processing that involves applying knowledge of disease and medications (Smith, Francis, Gray, Denham, & Graffy, 2003). Prior work examining caregiver medication administration has been conceptualized to include information seeking and sharing, safety issues, scheduling logistics, and polypharmacy concerns (Travis et al., 2000, 2003). Additional skills in opioid use may include responding to side effects, interpreting response to medications, and medicating around the clock (Letizia et al., 2004).

In summary, medication management is an important family caregiving responsibility that encompasses a complex set of cognitive, problem-solving, and interpersonal skills and processes. This paper describes results from qualitative interviews with hospice providers and family caregivers to provide a more concrete definition of caregiver skills related to medication management for hospice patients.

METHODS

Design and Study Sample

To obtain a comprehensive view of medication management skills, we conducted face-to-face interviews with a purposive sample of hospice providers and family caregivers of elderly home-hospice patients who were receiving services from four large hospice programs in the Chicago metropolitan area. In keeping with our qualitative study design, we aimed not for statistical representativeness but rather for a diverse sample of professional and family caregivers with knowledge or experience to provide in-depth insight into medication management skills.

At each hospice site, we worked with executive directors, medical directors, clinical managers, and/or hospice nurses to identify and recruit study participants. Inclusion criteria for *hospice providers* were clinical contact with patients and family caregivers. We recruited at least one physician, one registered nurse, and one social worker from each site. Of the 26 hospice providers contacted, 22 providers participated: 14 registered nurses, 4 physicians, and 4 social workers. Four other nurses declined because of scheduling conflicts.

Inclusion criteria for *family caregivers* were ≥ 18 years old, English-speaking, and responsible for assisting elderly

Table 1. Family Caregiver Characteristics

Characteristics	No. (total = 23)	% (100)
Relationship to patient		
Daughter	10	43
Wife	4	18
Husband	2	9
Significant other (1 male, 1 female)	2	9
Sister	2	9
Son	1	4
Granddaughter	1	4
Neighbor	1	4
Age ($M = 62.2$; $SD = 15.7$)		
Less than 50 years old	4	17
51–70 years old	13	57
Greater than 70 years old	6	26
Sex		
Female	18	78
Male	5	22
Race/ethnicity		
White	11	48
Black	9	40
Latino	1	4
Asian	1	4
Other	1	4
Highest education attainment		
High school diploma or equivalent	12	52
College degree	4	17
Graduate/professional degree	7	31
Annual household income		
Less than \$20,000	6	26
\$20,001–\$50,000	6	26
Greater than \$50,000	10	43
No response	1	4
Currently employed		
Yes	7	31
No	16	69
Prior health care training		
Yes	3	12
No	20	88
Time helping patient with medications		
Less than 1 year	6	26
1–10 years	12	52
Greater than 10 years	5	22
No. of medications patient is taking		
1–5	11	48
6–10	9	40
Greater than 11	3	12
Patient's length of hospice stay		
Less than 1 month	1	4
1–6 months	19	84
Greater than 6 months	3	12
Patient's primary hospice diagnosis		
Alzheimer's disease and related dementia	8	35
Cancer	8	35
Congestive heart failure	3	12
Chronic obstructive pulmonary disease	1	4
Kidney failure/diabetes	1	4
Uncertain	2	9

hospice patients (≥ 60 years old) with medications at home. Clinical managers and hospice nurses at each study site identified a convenience sample of eligible family caregivers who were either existing clients at the start of recruitment or new clients after the recruitment process began. Of the 28 family caregivers contacted by the study investiga-

tors, 23 caregivers participated. Of the 5 who refused, 2 declined without any reason and 3 declined due to scheduling conflicts; no additional information was obtained from them. In all, we conducted 45 interviews: 22 hospice providers and 23 family caregivers.

Most hospice providers were female (73%), White (82%), and had worked in hospice for 3 or more years (60%). One African American and three Asian American providers participated. Table 1 shows family caregiver characteristics. Most family caregivers were daughters (43%), female (78%), between 51 and 70 years old (57%), White (48%) or African American (40%), and at most high school educated (52%). About 26% of caregivers reported annual household income less than \$20,000 and 43% reported more than \$50,000. Most caregivers were not employed (69%) and had no health care training (88%). Almost all caregivers had helped a patient who was enrolled in hospice for more than 1 month (96%) and most had assisted the patient with medications for more than 1 year (74%). Most caregivers were helping patients with Alzheimer's disease or related dementia (35%) or cancer (35%).

Interviews

Interviews were guided by a semistructured, open-ended questionnaire. Trigger questions were asked to explore participants' conceptualizations of medication management. For hospice providers, trigger questions addressed *knowledge* ("What should family caregivers know to help a patient with medications at home?"), *concerns* ("What concerns have family caregivers expressed about helping with medications?"), and *skills* ("What medication-related mistakes do family caregivers make?").

For family caregivers, questions addressed *knowledge* ("What medication-related information have you learned or want to learn?"), *attitudes* ("What worries do you have about helping with medications?"), and *skills/responsibilities* ("Describe how you help the patient with his/her medications." "What advice would you give to other family members with similar medication responsibilities?").

Additional probe questions were asked to prompt respondents for further elaboration and examples. Hospice providers were asked about the normative skills that they believed caregivers should have and about caregiving behaviors they encountered in their clinical practices. Family caregivers were asked about their individual experiences and skills.

Data collection occurred between March and July of 2008. Interviews with hospice providers were conducted at a location of the subject's choice: 20 interviews occurred at the provider's office and 2 at the investigator's office. All 23 interviews with family caregivers were conducted at the caregivers' place of residence. Interviews averaging about 1 hr in length were conducted by D.L. and L.H. and were audio recorded with written consent and later transcribed. This study was conducted according to the protocol approved by the Institutional Review Board at the lead investigator's institution.

Table 2. Family Caregiver Skills in Effective Medication Management for Home Hospice Patients (with illustrative examples)

1. Teamwork skills
Able to communicate with hospice providers (e.g., for various medication-related reasons, at any time)
Able to coordinate with multiple family caregivers or hired caregivers (e.g., assign point person, establish communication channels, address conflicts)
2. Organizational skills
Able to acquire, store, track, and discard medications (e.g., arrange delivery, keep medications away from children, record medications given and to be given, discard used syringes and patches properly)
3. Symptom knowledge skills
Able to respond to common symptoms and drug side effects (e.g., distinguish and react to “expected events” and “crisis” appropriately)
4. Medication knowledge skills
Able to apply the basics of pharmacology (e.g., understand time to peak effect and maximum dosage)
Able to apply knowledge of the symptom-relief kit (or comfort kit) (e.g., know when to call hospice and use contents in the kit)
Able to administer different types of medications
—Pills, liquid medicines, and transdermal patches (e.g., do not crush extended-release pills; administer sublingual liquid medicines under the tongue; rotate site of application for patches)
—As-needed medications (e.g., administer medications according to the patient’s symptoms)
—Opioids (e.g., know the myths of opioids, balance therapeutic and side effects)
5. Personhood skills
—Able to assess, monitor, and interpret the patient’s health condition (e.g., interpret verbal and non verbal cues, record symptom changes)
—Able to administer medications and provide care to the patient (e.g., work with patients who resist or cannot take medications)

Analysis

Atlas.ti v-5.2 software was used to facilitate coding and content analysis. Topic and thematic codes were initially developed by D.L. and later reviewed and validated by research assistants J.M. and L.H. (Glaser & Strauss, 1967). Biweekly team meetings were held to discuss coding definitions and strategies and to reach group consensus on discrepant codes to ensure analytical consistency (Miles & Huberman, 1994). Codes were developed to document recurrent skills that emerged from the data using an iterative process of comparison and evaluation across interviews. Similar skills were further grouped into common categories. For example, study participants discussed the skills necessary to apply transdermal patches properly. These skills were grouped with other skills related to administering different types of medications (e.g., pills and liquid medicines).

RESULTS

Overall, hospice providers and family caregivers identified similar skill sets for medication management. However, hospice providers generally emphasized technical skills such as administering medications properly, especially opioid analgesics, because they believed that these skills

were most important and caregivers required most assistance with them when caring for patients. On the other hand, family caregivers more frequently emphasized their day-to-day responsibilities and highlighted management skills such as organization (storing and tracking medications), teamwork (especially coordinating with hired caregivers), and personhood (especially understanding how to provide care to patients who refused treatment). Participants were not asked to rank skills in terms of the degree of importance.

We propose a theoretical construct for *family caregiver skills in effective medication management for hospice patients* that is grounded in the themes and topics reflected in the interviews. Based on participant perspectives, we propose that effective medication management in this setting is the ability to effectively relieve symptoms with pharmacological interventions by successfully utilizing caregiving skills in the following five domains: teamwork skills, organization skills, symptom knowledge skills, medication knowledge skills, and personhood skills (Table 2). Each domain is discussed in detail below. When relevant, differences between the views of hospice providers and family caregivers are highlighted. Although many of the skills identified by participants were concrete, they are not discrete. Instead these skills are inter-related, sometimes in complex ways that may change over time. For example, how and when a caregiver administers medications can be influenced by the ongoing development of skills in all other areas as well as the changing conditions of the patient.

Teamwork Skills

Teamwork skills encompass the ability to communicate and coordinate with hospice providers, other family caregivers, and additional hired caregivers. Both hospice providers and family caregivers discussed the importance of knowing when to contact hospice and being a good communicator with the hospice team. A nurse suggested, “[Caregivers] should call hospice anytime if there are any questions, if they miss any doses, if the patient is experiencing uncontrolled symptoms, or if there was a sudden change in health condition.” However, some caregivers would not contact hospice for assistance because “they don’t understand the 24/7 hospice support,” “they are embarrassed to say they don’t know what to do,” or “they think they are pestering the nurse.”

Some caregivers sought to be good communicators by being prepared and informed about the patient’s condition, asking follow-up questions to clarify any confusion, and taking relevant notes to remember instructions. A daughter observed, “If something comes up, I always pay attention to when it started and what happened around that time. I have to know the information so that when the nurse asks I can tell her.” However, a daughter who did not take notes while talking to hospice said, “We ran out of the pills before it was time to refill. Later I remember the doctor telling me to start giving the drug [fewer times] a day. I forgot to write that down.”

To coordinate among multiple family caregivers, a nurse advised that, whenever possible, caregivers needed to either “assign one primary person to administer medications and communicate with hospice” or “draw up a schedule to track which caregiver will give the medications and at what time.” The coordination problem was evident in an incident that a nurse recalled: “A wife administered the medications without letting her husband know. The patient had double dosage of the drug when the husband gave the drugs again.” However, hospice providers acknowledged that family coordination was especially difficult when there were deep-seated family conflicts. A nurse said, “There are many ulterior motives that I don’t know about. A child who has never cared for the patient may feel the need to step in to help. The rest of the family is thinking, ‘Oh now you want to help? Where were you when this and this was happening?’”

More family caregivers than hospice providers discussed the need to be resourceful in managing hired caregivers (e.g., home assistants and nurse’s aides). A daughter said, “I check up on [the hired caregiver] by asking her questions like ‘When did you give the medications to my mom?’ If she comes up with a different time, then she didn’t follow the instructions.” Another daughter took charge when her hired caregiver was reluctant to administer morphine. She said, “I told her, ‘I am telling you now, you may not agree with this, but you are going to give this drug to my mom.’” In another example, a daughter acknowledged that her prior caregiving experience with her mother helped her coordinate better with the hired caregiver while she was helping her dad in hospice; she said, “I will email and telephone. I have a journal that everyone writes in everything about how my dad is doing and what drugs were given.”

Organizational Skills

Organizational skills include the ability to acquire, store, track, and discard medications. Because most patients took hospice- and nonhospice-prescribed drugs, caregivers discussed how they acquired the medications and understood policies concerning coverage and copayment, delivery and pickup procedures, and ordering and refilling medications. To properly store medications, especially opioids and other controlled substances, caregivers explained the importance of keeping medications away from children and anyone who may misuse those drugs. A daughter added, “When [the patient] is throwing up or pooping everywhere, you don’t have the time to figure out where to find the drugs you need.”

Although both hospice providers and family caregivers discussed its importance, more caregivers emphasized the importance of properly tracking medications to facilitate drug administration (e.g., know who, when, and which medications to give), error checking (determine if a scheduled dose was skipped), refills (order medications in advance to avoid running out of the drugs), and communication

with others (tell hospice what medications were given). Tracking methods ranged from detailed handwritten and electronic logging systems to simple calendars and pill-boxes, depending on caregivers’ preferences, technological skills, and access to technologies. Many caregivers who kept detailed documentation attributed their organization skills to their employment experience. A husband explained that his engineering background helped him track his wife’s health condition and drug regimen; a daughter discussed her experience as a schoolteacher who kept detailed records of her students.

To avoid drug diversion, hospice providers discussed the importance of properly discarding transdermal patches, used syringes, or expired medications in such a manner (e.g., disposing of medications in the sink or toilet) that the disposed drugs could not be easily retrieved by others.

Symptom Knowledge Skills

Symptom knowledge skills encompass the ability to recognize and respond to common symptoms at the end of life. Hospice providers emphasized the importance of recognizing major health changes that differed from baseline condition. A social worker commented, “In hospice, a lot of things are considered ‘expected events’ and not considered a ‘crisis.’ [Caregivers] should understand what the typical disease process would look like and what type of care would be involved so that they have some expectation.” Many caregivers who did recognize common signs of distressing symptoms credited their experience caring for other family members in hospice. A sister said that her experience caring for her mother and husband when they were in hospice helped her assess her brother’s health condition. However, a daughter who had no caregiving experience said, “When my mom started grinding her teeth, the nurse asked me if I thought about giving her medicine for anxiety. But I didn’t know what the symptoms meant.”

Family caregivers discussed the emotional benefits they felt from knowing how to respond to symptoms. A daughter said, “[The nurse] described all the things I need to look out for and how the cancer will affect [my mom’s] body. So now I am prepared for those things and know how to handle them.” However, a wife lamented, “I kept asking but hospice was not straightforward in telling me what symptoms to expect. They might think they were trying to protect me but instead I felt patronized and ill-prepared.”

Medication Knowledge Skills

Medication knowledge skills include the ability to apply the basics of pharmacology, including understanding the difference between generic and brand names, time to peak drug effect, the difference between short-acting/fast-release and long-acting/extended-release drugs, and the danger in double dosing. For example, a wife had difficulty communicating with hospice providers because she did not understand

the difference between generic and brand names; she admitted, "The nurse called the drug lorazepam and I didn't think I had it. It turned out to be Ativan but I didn't know there are two names." Regarding time to peak effect, a nurse said, "A [caregiver] called me because [the patient] was not getting relief. When I arrived 30 minutes later, she was sound asleep. The [caregiver] did not know how long to wait before the drug took effect." A social worker also said, "[Caregivers] should give extended-release pain medications to keep the patient in the comfort zone and fast-acting drugs to relieve breakthrough pain." Further, a nurse advised, "If a dose is skipped, [caregivers] should never double-dose."

More hospice providers than family caregivers highlighted the technical aspects of administering medications, including "as-needed" medications and opioids. If medications in pill form were prescribed, providers said that family caregivers should not crush extended-release tablets. A physician said, "I've been called about somebody who was chewing his opioid tablet. It's long acting so [the caregiver] should have stopped that. The patient was all sedated at once and the drug didn't last for 12 hours." A nurse cautioned that if liquid medicines were prescribed, caregivers should pay attention to the units of measurements and not confuse milliliters and milligrams. Hospice providers also highlighted skills for properly applying transdermal patches, such as rotating the site of application to avoid irritation and not cutting patches.

When as-needed medications were prescribed, both hospice providers and family caregivers discussed the importance of monitoring changes in symptoms and adjusting medications according to prescription. A daughter who had prior health care training said, "If my mom is short of breath, first I check her breathing. I ask her and she usually says, 'Yeah, I am out of breath' but not all the time. So I give her some oxygen. Wait five minutes. I check her breathing again. If she still looks or says she is still short of breath, I will give her two drops of morphine. Wait five minutes and check again." However, caregivers may fear over-medicating a patient with as-needed medications. A physician noted, "Some [caregivers] fear giving too much drugs. They give [the minimum amount] even when the patient is still constipated or in severe pain." Some caregivers also did not understand the difference between as-needed and scheduled medications. A physician cited a situation in which "[a caregiver] was instructed to give a prn medication every 4 hours as needed but she gave it every 4 hours around the clock."

Hospice providers emphasized the importance of caregivers understanding that opioids are effective medications if administered properly. Providers said some caregivers resisted using opioids because they feared that "patients will become addicted," "morphine should be used when [the patient] is about to die," or "opioids will speed up the dying process." When opioids are prescribed, providers believed that caregivers should administer an optimal dosage that would maximize pain relief and minimize drowsiness and

constipation. However, this was challenging for caregivers who valued alertness. A daughter said, "I don't give [my mom] morphine during the day. I'd rather have her interact with people than have her being zonked out."

Many caregivers were given a symptom-relief kit that contained fast-acting, prn medications for distressing symptoms. Hospice providers said that in the event of a sudden decline in the patient's health, caregivers should call hospice and be prepared to administer the medications under hospice directions. A nurse explained, "The kit is for [caregivers] to give the patient the initial dose so that we can start helping immediately before a nurse can arrive to evaluate further." However, a wife misunderstood the purpose and said, "In an emergency, I will call hospice. I will not give the medications [in the kit]. The nurse would come and do that."

Personhood Skills

Personhood skills encompass the ability to assess the patient's symptoms and administer medications given the patient's individual needs, preferences, and ways of communication. Whereas the two previous domains focused on general knowledge of pharmacology and symptomatology, this domain focused on understanding and caring for the patient as a person by integrating general medication and disease knowledge with the specific understanding of the patient's health conditions and wishes.

Both hospice providers and family caregivers discussed how caregivers should know how to assess and interpret the patient's health condition by incorporating specific knowledge about how the patient expressed discomfort (e.g., verbal and nonverbal cues) with general knowledge about what symptoms were common near the end of life. Particularly important was caregivers recognizing common signs of pain and interpreting pain as exhibited in the patient. A daughter who had cared for her mother in hospice for more than 2 months said, "When my mom needs pain medicine, she will breathe very fast and sweat around her forehead. During her sleep, I know she is in pain if she grips hard onto something. Certain little things you watch for."

Finally, more family caregivers than hospice providers emphasized the frustrations caregivers experience when patients actively refused their medications. Caregivers discussed how they needed to be respectful to the patient while being resourceful in their response, such as mixing the drug with palatable food, crushing appropriate pills, encouraging the patient, or giving the medicines at a later time. A daughter added, "She may not have control over her dying but she's got control over the way she dies. My advice is to take a break and try again later."

DISCUSSION

Providing symptom relief using medications is the cornerstone of palliative and hospice care. Because home hospice patients depend on family members to provide many

aspects of care, a comprehensive understanding of medication management skills may better prepare caregivers as medication managers to provide effective symptom relief to patients. Based on this qualitative, interview-based study, we propose a theoretical construct of *family caregiver skills in effective medication management for hospice patients*. The construct consists of skills categorized into five distinct yet interrelated domains—teamwork, organization, medication knowledge, symptom knowledge, and personhood.

These domains capture a comprehensive set of skills informed by the perspectives of hospice providers and family caregivers. Although both groups identified similar skill sets, there were differences of emphasis. Hospice providers generally emphasized technical skills related to the administration and management of medications. Family caregivers emphasized day-to-day responsibilities related to organization, teamwork (especially coordinating with hired caregivers), and personhood (especially understanding how to provide care to patients who refused treatment).

Although we focus on skills specific to medication management in hospice, broader life experience also played a role in skill development for many caregivers. Almost three quarters of the caregivers in this study had assisted their patients with medications for over 1 year, and many spoke about their experience helping other family members. The accumulation of caregivers' life experience in caring for a dying patient is consistent with a previously articulated "trajectory" model of long-term illness, which refers not only to the physiological progression of a patient's disease but also to the "total organization of work," which includes the life experiences of all the care providers involved (Strauss, Fagerhaugh, Suczek, & Wiener, 1985). In the case of hospice medication management, caregivers attributed some of their teamwork and organizational skills to skills they learned during previous jobs. Others attributed their ability to recognize common symptoms and monitor medications to prior self-care or family caregiving responsibilities.

Other factors, such as health literacy, functional limitations, and family conflicts, may affect medication management skills of family caregivers and, therefore, may need to be considered in future studies. Health literacy, an individual's "capacity to obtain, process, and understand basic health information" (Healthy People 2010, 2000; Institute of Medicine, 2004), may influence the development of medication management skills. Although the proposed construct does not explicitly include health literacy as a distinct component, we believe that adequate functional health literacy may be foundational for some skills involving health information, such as comprehending prescription drug labels and other printed materials for administering medications. Communication with hospice providers also may be affected by health literacy because of differences in education between hospice providers and family caregivers. Understanding how health literacy and education are associated with medication management skills will assist hospice providers to

better tailor their care delivery and inform future development of training interventions in this area.

Because our intention was to identify medication management skills that can be improved through training and experience, the proposed construct does not include skills that are associated with physical or cognitive impairment (e.g., a family caregiver's inability to hold a liquid dropper). Because many family caregivers are aging spouses or partners of hospice patients, physical or cognitive impairment among caregivers is likely to be of concern. Furthermore, caregiving may involve complex situations that may be beyond the caregivers' control, such as family conflicts. We believe that future interventions can be designed to improve caregivers' skills to communicate effectively with other family members. The limitations of improved caregiver skills in the presence of difficult family situations will need to be examined.

The proposed construct contributes to the fields of caregiving and medication management. The growing body of literature related to caregiver skills has mainly focused on the general processes of caregiving for cancer patients (Schumacher et al., 2000) or coping abilities (McMillan & Small, 2007). This study contributes to previous research by providing a focused, in-depth analysis of caregiving skills in the management of prescribed drugs in hospice. Consistent with previous work, our study finds that the development of medication management skills involves a process of accumulating skills over a lifetime and that providing care using medications requires both general knowledge of disease and treatment as well as specific knowledge of the patient's preferences and behaviors. Most studies of medication management have examined skills related to adherence or specific tasks (Buelow & Smith, 2004). Our findings contribute to this literature by describing a comprehensive set of skills involving multiple processes such as coordinating with other caregivers and interpreting symptoms that go beyond passively following instructions. Expanding on previous work on caregiver medication administration for the general elderly population (Travis et al., 2000, 2003), our work finds that administering as-needed medications properly is particularly important to the home hospice elderly population.

Our findings provide a conceptual basis for the future development of a comprehensive instrument for assessing caregiver medication management skills. Hospice providers discussed how they assessed family caregivers' skills on an ad hoc basis, including observing caregivers administering drugs, examining pillboxes to determine missed doses, or asking caregivers to repeat back instructions. However, these methods are not comprehensive, standardized, or empirically tested. There is a clear need for a psychometrically validated tool that will help hospice providers identify caregivers who need further training in medication management. The skills identified in this study will inform the future development of this assessment tool.

Our findings also provide a conceptual foundation for developing a comprehensive and tailored training intervention for hospice providers and family caregivers. Most family caregivers acquire their skills on a trial-and-error or "learn-as-you-go" basis or from informal advice given by hospice and other health care providers. Our study indicates that in addition to properly recognizing symptoms and administering medications, family caregivers value skills in teamwork, organization, and personhood especially to patients who resist taking medications.

Although being highly skilled is arguably a prerequisite for good performance in medication management, other factors such as family caregivers' fatigue, grief, economic burden, and poor relationship quality with the patient can hinder actual caregiving performance, as well as impede willingness and capability to acquire new skills. Therefore, training interventions in skill development will need to be sensitive to caregivers' grieving process and be coupled with programs that will address the psychosocial and economic situations of caregivers.

Although this study provides a conceptual understanding of medication management skills, the findings cannot be generalized to the broader population of caregivers because the study design was based on qualitative data from a non-probabilistic sample. Our findings instead reflect the perspectives of individuals in our study sample. Our analysis demonstrates thematic saturation (the threshold after which no new significant insights or themes emerged) occurring for each study group (22 hospice providers and 23 family caregivers), numbers comparable with other qualitative studies (Guest, Bunce, & Johnson, 2006).

The validity and applicability of our proposed construct needs further investigation in other populations, including family caregivers of children receiving hospice care. Our study sample primarily includes family caregivers with long-term caregiving experience and is limited to only English-speaking caregivers living in the Chicago area. Family caregivers of less experience, other racial/ethnic groups, and other geographic locations should be studied to understand the impact of cultural and social factors on medication management skills. Other factors such as the complexity of the medication regimen and the patient's coexisting illnesses should be further examined to refine the proposed skills. Furthermore, the expansion of this work may lead to the study of hired caregivers, many of whom develop a strong familial relationship with the patient and are given varying degrees of medication responsibility.

As more hospice patients choose to die at home, greater emphasis is placed on family caregivers to ensure proper and safe use of medications to promote comfort care. This study provides a theoretical understanding of medication management skills that can guide future development of standardized training interventions and validated clinical assessment tools in this area. The work presented here will be relevant to practitioners, family caregivers, researchers,

and educators concerned with improving medication use at home and advancing the field of hospice care.

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